Genetic discrimination (GD) is one of the most pervasive issues associated with genetic research and its large-scale implementation. An increasing number of countries have adopted public policies to address this issue. Our research presents a worldwide comparative review and typology of these approaches. We conclude with suggestions for public policy development.

Genetic Discrimination

Research in genetics and related fields has already enabled the development of diagnostic and predictive tests as well as pharmacogenetic drugs [1]. Genetic information is also increasingly used outside the medical context for ancestry, paternity, and forensic investigations (Box 1). Within the past 30 years or so, GD – the adverse treatment or profiling of individuals, or their relatives, on the basis of their actual or presumed genetic characteristics – has become one of the most pervasive and mediatized issues associated with genetic research and its implementation in developed countries [2].

Similarly to racial, sexual, and ethnic discrimination, GD can lead to exclusion and loss of social opportunities; it is also strongly associated with psychological distress [3]. Anxiety about GD has been identified as an important reason why individuals decline to participate in genetic research or to undertake medically recommended genetic tests [4]. The potential for genetic information to be abused by society has been taken very seriously by the public and experts alike, giving rise to the concept of ‘genetic exceptionalism’ in the mid-1990s [5]. According to this viewpoint, genetic information is more sensitive than other types of medical information and should be protected more stringently.

Growing political activism has influenced policymakers in a large number of developed economies to adopt laws, policies, moratoria, and guidelines to prevent GD. Here we present a comparative overview of existing approaches worldwide (Figure 1).

Comparative Law and Policy Review (Figure 1)

In 1997, UNESCO’s Declaration on the Human Genome and Human Rights stipulated that ‘No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity.’ There is now a consensus among international organizations that the confidentiality of identifiable genetic information should be protected and that discrimination should be prevented. (Table S1 in the supplemental information online).

Regional and National Overview

Europe. Two legally binding regional instruments, the Charter of Fundamental Rights of the European Union (2012) and the Convention on Human Rights and Biomedicine (1997), have influenced members of the European community to develop national instruments to address GD based on the human rights approach. Furthermore, a recent recommendation of the Council of Europe (2016) proposes that insurers justify the processing of all health-related personal data and not require genetic tests, or use test results, for insurance purposes (http://www.quotidianosanita.it/allegati/allegato2027308.pdf).

The British government, preferring a different approach, has opted to prevent GD through a moratorium. This flexible and provisional solution was agreed upon by the government and the Association of British Insurers (ABI) in 2001 (in force until 2019). The moratorium prevents members of the ABI from using the results of predictive tests unless pre-approved by the government following consultation with independent experts. As moratoria are flexible, they can be easily updated to account for new scientific developments.

Another outlier that was not influenced by genetic exceptionalism is The Netherlands’ Law on Medical Examinations (1977) (unofficial translation). In this law access to medical information by insurers depends on the level of coverage...
Worldwide normative approaches to address genetic discrimination

Countries are considered as "having an approach" whether the said approach addresses genetic discrimination specifically in part, or broadly.

<table>
<thead>
<tr>
<th>APPROACH</th>
<th>SUMMARY</th>
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<tr>
<td>Human Rights</td>
<td>This approach aims to provide a broad, human rights-based protection against genetic discrimination in a country's human rights legislation.</td>
<td>Alberta, Law No. 150 (discrimination based on genetic characteristics)</td>
<td>Broadly formulated, prohibition not modular to judicial interpretation and administrative exceptions, offers degree of flexibility of interpretation.</td>
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<td>Genetic exception</td>
<td>This approach consists of creating a specific exception for genetic information in other types of health or personal information in sector-specific, user-oriented, protections.</td>
<td>Ontario, Human genetics research Act (2005), and amendments (2013)</td>
<td>Approach assumes that genetic information is more sensitive than biomedicine but not yet_sectorialism/new geneticism/spitualism.</td>
</tr>
<tr>
<td>Sectoral prohibitions</td>
<td>This approach aims to prevent the processing of genetic information specifically addressed through the use of prohibitive clauses in sectoral regulations such as employment, immigration, or insurance laws.</td>
<td>United States, Genetic Information non-Discrimination Act (2008)</td>
<td>Application limited to specific types of stakeholders or limited instances of GD. Often formulated too narrowly to protect against GD based on new types of OMS data and any privacy history of illness.</td>
</tr>
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<td>Ethical guidance</td>
<td>Guidelines may be fairly broad in scope and subject to changing. They may have a status quo approach, or may require ongoing updating as the specific context.</td>
<td>Non-regulatory, ethical guidance, policies (2017)</td>
<td>Difficult to enforce. Useful to stimulate debate as well as to prevent the development of more stringent laws and policies.</td>
</tr>
<tr>
<td>Self-regulatory</td>
<td>Under this approach, professional organizations have created policies for genetic information for all settings (custom fit governance model).</td>
<td>Self-regulatory, human genetics research Act (2005)</td>
<td>Relevant for product specific sector and non-regulatory issues. Good model whenGD does not differ in value and scope of protection and risk. It can also be easily modified to account for some types of predictive data or emerging contexts of GD.</td>
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<td>Moratoria</td>
<td>This approach consists of an agreement between a representative professional organization and the government, that is to be kept under the legal and genetic information.</td>
<td>Non-regulatory, ethical guidance, policies (2017)</td>
<td>Non-regulatory, human genetics research Act (2005)</td>
</tr>
<tr>
<td>Status quo</td>
<td>Stakeholders have not taken any specific action to address GD. There may still be stakeholders through the use of prohibitive clauses in sectoral legislation such as employment, immigration, or insurance laws.</td>
<td>No special regulatory, human genetics research Act (2005)</td>
<td>Non-regulatory, human genetics research Act (2005)</td>
</tr>
<tr>
<td>Hybrid</td>
<td>Some countries have integrated relevant issues into existing sectoral policy to develop a more accessible, more layered, more practical framework.</td>
<td>Self-regulatory, human genetics research Act (2005)</td>
<td>Custom hybrid governance that includes aspects of different approaches to provide a more layered degree of protection.</td>
</tr>
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</table>

Figure 1. Worldwide Normative Approaches to Address Genetic Discrimination (GD).

being sought. This approach provides for universal access to a minimum “no questions asked” level of insurance.

North America. Given Canada’s universal health-care system and the limited number of documented Canadian cases of GD, policymaking initiatives have been limited. However, the political momentum in Canada has recently swung in favor of the adoption of a legislative solution. Bill S-201, the Genetic Non-Discrimination Act, was adopted by the Canadian parliament in December 2017 and is now awaiting Royal Assent. It could be subject to constitutional challenges in the coming months. It proposes both a human rights approach, based on genetic characteristics, and a sectoral prohibitive approach to GD. Rather belatedly, Canadian insurers reacted to the growing pressure to regulate GD by promulgating their own industry code, which was updated in January 2017 to include a stipulation that insurers would not “use genetic test results for life insurance coverage of $250,000 or less”.

In the USA, the issue of GD is particularly contentious due to the absence of a universal health-care system meaning that access to personal insurance is usually tied to employment. Moreover, claims of GD appeared for a limited number of monogenic diseases early in the advent of the Human Genome Project [2]. In response there is now a patchwork of state laws on GD in various contexts and for various diseases. Following lobbying by patient groups and genetic researchers, the Federal Congress imposed a common minimal threshold across the country through the American with Disabilities Act, the Health Insurance Portability and Accountability Act, the Genetic Information Nondiscrimination Act, and the Affordable Care Act. However, the complex US federal framework does not extend to the field of life insurance, for which the only protection available is at the state level, if any.

Recently, the Mexican government rallied to the human rights approach by amending both its Federal Law to Prevent and Eliminate Discrimination (2014) and its General Healthcare Law (2015) to include a general prohibition on discrimination based on the genetic characteristics of an individual.

South America. Most South American countries have yet to address the question of GD in their laws or policies. Given the more modest standards of living, the limited capacity to perform genetic tests, and the costs of insurance, GD is not a priority in this region. Only Chile has provided national protection to its citizens via legislation from GD based on the genetic exceptionalism approach. Argentina has adopted city-specific legislation, such as the 2001 Law of Genetic Patrimony of Buenos Aires (author’s translation), which presents a hybrid approach integrating human rights and sectoral prohibitions.

Australasia. Australian researchers have conducted a large-scale investigation of GD in their country [6,7]. The Australian
The capacity of the approaches we have described to effectively address incidents of GD has been considered in only a few studies [2, 7, 9]. Existing models generally suffer from several important limitations: (i) lack of public visibility; (ii) restrictive, rigid formulation; (iii) narrow protection; and (iv) complex administrative procedures.

In addition to these challenges it is likely that a large number of GD cases will not be prevented by these approaches since they were developed to address GD in the context of highly heritable monogenic diseases. Other types of GD and other sources of predictive information are inconsistently addressed by existing norms. Moreover, the laws of most countries liberally sanction the use of genetic information by government to control immigration and prevent crime. The sheer amount of genetic data contained in governmental databases in developed economies warrants the development of more stringent oversight and accountability frameworks.

An implicit question raised by these observations is whether law is truly the best vehicle to address GD. By increasingly deciding to single out, regulate, and protect genetic information, are we not also fostering genetic exceptionalism and the stigmatization of certain types of genetic profiles considered ‘at risk’? While legislation may help prevent GD, there could be an even greater need to actively engage stakeholders on the potential and limits of genetic technologies, existing protections, and the need to express greater solidarity in integrating genetics in everyday life. We substantially share our genome with our relatives, our neighbors, and the entire human species, which provides an impetus for giving greater weight to the ethical principle of solidarity in addressing GD.

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Supplemental Information

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Resources


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